American Spinal Injury Association (ASIA) 40th Anniversary: Beginnings, Accomplishments and Future Challenges

Kristjan T. Ragnarsson, MD

Lucy G. Moses Professor and Chairman, Department of Rehabilitation Medicine, Icahn School of Medicine at Mount Sinai, New York, New York

G. Heiner Sell

It is a great honor for me to be invited to give the G. Heiner Sell Lecture at the 40th Anniversary of the American Spinal Injury Association (ASIA). It is also very personal for me because Heiner Sell was my best friend and our families have always been close. We worked together during the week and played tennis together on the weekends.

Given my close personal relationship with Heiner, I was asked to tell you a little about him and how this lectureship in his name came to be. Afterwards, I will discuss the early history of ASIA and how ASIA members have influenced and improved the care of persons with spinal cord injury (SCI) over the last 40 years. If time permits, I will share my thoughts with you on how ASIA can continue to positively influence SCI research and clinical care.

Heiner was born in Germany in 1938, the son of a physician. After graduating from medical school in Munich, he came to the United States with his wife, Irmgard, during the mid 1960s to specialize in the field of Physical Medicine and Rehabilitation (PM&R) with Dr. Howard A. Rusk at New York University Medical Center. I first met Heiner in 1970, when I came to be interviewed for a residency position at NYU. He immediately impressed me with his enthusiasm and personal warmth.

During my residency and fellowship, Heiner was one of my teachers. Later, he was my partner in

This was presented at the Plenary Session at the ASIA Annual Meeting in Chicago, Illinois, May 6, 2013.

Top Spinal Cord Inj Rehabil 2013;19(3):153–171

www.scijournal.com

doi: 10.1310/sci1903-153

practice and collaborator in research. Heiner met all my criteria of what a physician and a leader should be. He was objective and hard working, but still he was always kind and pleasant. He was a good listener, but analytical and persuasive in his comments and decisive in his actions. He constantly looked for answers to the numerous research questions relating to care of people with SCI and was relentless in pointing these out to his colleagues, encouraging them to seek greater understanding by conducting research.

Heiner had a great influence on my personal and professional life. After completing my SCI fellowship in 1975, I returned with my family to my native country of Iceland. Heiner convinced me to return to the United States the next year, just for a few years or until the SCI Model System Grant ran out. I was planning to return to Iceland again in 1981 when Heiner got ill with cancer and was unable to return to work. I cancelled all my plans, took care of our practice, and was named the PI on our SCI Model System Grant. Where I and my family were going to live seemed such a trivial concern compared to what Heiner and his family were going through.

Heiner was one of the doctors who developed ASIA as an organization during the 1970s. He was to follow Ed Carter and Paul Meyer, the first and second presidents of ASIA, and become the third president of ASIA in the spring of 1981. Unfortunately, fate would have it otherwise. In early January 1981, he became ill with cancer and never returned to work after that. He died less than 4 months later. He was just 43 years old. Instead of Heiner, another physician of great distinction, Samuel Stover, became the president of ASIA.

After Heiner's death, Paul Meyer led the way to establish a distinguished annual lectureship in the name of Heiner Sell. When inflation and expenditures eroded the initial funds, members of ASIA and friends of Heiner started a new fundraising drive during the 1990s and increased the value of the fund from less than $10,000 to more than $200,000 by the late 1990s.

Since 1982, the Sell Fund has made it possible for ASIA to invite leading basic scientists as well as outstanding clinicians and clinical investigators to present their work at the Annual Scientific Meetings (**Table 1**). Given the accomplishments of the previous Sell lecturers, I feel humble to be in their company.

As the Sell Fund grew, the Board of ASIA decided to broaden the purpose of the Fund to also support certain educational and research programs relating to the care of people with SCI. I am extremely grateful to all who have donated to the Sell Fund and thus helped to keep alive the name of my dear friend and great colleague.

Creation of ASIA and the SCI Model Systems of Care

ASIA was not born in a vacuum. During World War II, SCI units were created at a few military hospitals and after the war at several Veterans Affairs (VA) hospitals. In 1954, under the leadership of Ernst Bors, Estin Comarr, and others, the American Paraplegia Society (APS) was founded, primarily for SCI physicians within the VA system. APS became completely inactive during the mid-1960s, but was revived with the encouragement and financial support of James Peters, President of the Eastern Paralyzed Veterans Association (EPVA), in 1973.

During the 1960s, American physicians treating patients with SCI outside the VA hospital system had been seeing each other at meetings of the International Medical Society of Paraplegia (IMSOP) and at SCI instructional courses in the United States. At these meetings, they shared their "problems and frustrations," which "proved to be valuable psychological infusions," according to Ed Carter,[1] who was one of the most effective leaders among ASIA's founders.

The most important stimulus for the creation of ASIA was the establishment and funding of the SCI Model Systems of Care by the Rehabilitation Services Administration (RSA) in the early 1970s. Ever since their inception, the Model Systems and ASIA have coexisted like two faces of the same coin. The majority of ASIA's presidents and board members have served as principal investigators or co-investigators on Model Systems grants. It is impossible to discuss the impact of ASIA on SCI care without addressing and giving credit to the Model Systems. The Model System grants have provided ASIA members with the funds to conduct data collection and clinical research,[2] and ASIA has

Table 1. G. Heiner Sell Lecturers at the Annual Scientific Meetings of the American Spinal Injury Association

1982	J. Paul Thomas, Washington, DC – "Spinal Cord Dysfunction: A Unique Model for American Medicine"
1983	R. Edward Carter, MD, Houston, TX – "Respiratory Function in SCI"
1984	Albert J. Aguayo, MD, Montreal, Quebec – "Axonal Regeneration from the Adult Mammalian Brain and Spinal Cord"
1985	P. Hunter Peckham, PhD, Cleveland, OH – "The State of the Art in Functional Electrical Stimulation"
1986	John Doyle, Washington, DC – "Renewal with Challenge for a Specialty Disability Group: The Spinal Cord Injured"
1987	Edward J. McGuire, MD, Ann Arbor, MI – "Fertility in SCI Patients"
1988	Bernard Towers, MD, Los Angeles, CA – "Quadriplegia and Life Extension: Who Decides?"
1989	David C. Viano, PhD, Detroit, MI – "Cause and Control of SCI in Automobile Crashes"
1990	Martin E. Schwab, PhD, Zurich, Switzerland – "Inhibitors of Neurite Growth: Role in CNS Regeneration"
1991	V. Reggie Edgerton, PhD, Los Angeles, CA – "A Physiological Basis for Development of Rehabilitative Strategies for Spinal Injured Patients"
1992	John F. Ditunno, Jr, MD, Philadelphia, PA – "ASIA Standards 1992: Past and Future"
1993	Robert R. Menter, MD, Englewood, CO – "Aging and SCI: Exploring the Unknown"
1994	Paul J. Reier, PhD, Gainesville, FL – "Neural Tissue Transplantation and SCI: Bridging the Gap Between Basic Science and Clinical Reality"
1995	William C. de Groat, PhD, Pittsburgh, PA – "Mechanisms Underlying the Recovery of Lower Urinary Tract Function Following SCI"
1996	Charles H. Tator, MD, PhD, Toronto, Ontario – "Experimental and Clinical Studies of the Pathophysiology and Management of Acute SCI"
1997	O. Lars Olson, MD, Stockholm, Sweden – "Spinal Cord Repair Strategies, Current Possibilities and Limitations"
1998	Giles S. Brindley, MD, London, England – "Neuroprostheses in SCI"
1999	Ake Seiger, MD, PhD, Stockholm, Sweden – "Human Fetal CNS Tissue Transplantation to the Injured Spinal Cord"
2000	Susan J. Harkema, PhD, Los Angeles, CA – "Sensory Processing by the Human Lumbosacral Spinal Cord During Locomotion: Implications for Recovery of Walking after Neurologic Injury"
2001	Mary B. Bunge, PhD, Miami, FL – "Transplantation Strategies to Improve Regeneration in the Adult Spinal Cord"
2002	Michal Schwartz, PhD, Rehovot, Israel – "Fighting the Consequences of SCI by Harnessing the Immune System: Prospects for Therapeutic Vaccination"
2003	Barbara S. Bregman, PhD, Washington, DC – "Transplants and Neurotrophic Factors Increase Regeneration and Recovery of Function After Spinal Cord Injury"
2004	Gale G. Whiteneck, PhD, Englewood, CO – "Measuring and Modifying SCI Outcomes"
2005	Claire E. Hulsebosch, PhD, Galveston, TX – "Treatments for SCI: Disproving the Edwin Smith Papyrus"
2006	Volker Dietz, MD, Zurich, Switzerland – "Neuronal Plasticity after SCI: Significance for Present and Future Treatments"
2007	Arthur Prochazka, MD, Alberta, Canada – "New Technologies in Spinal Cord Injury Management"
2008	Mark Tuszynski, MD, PhD, San Diego, CA – "Enhancing Plasticity and Regeneration after SCI: Challenges of Clinical Translation"
2009	Jonathan R. Wolpaw, MD, Albany, NY – "Using Spinal Cord and Brain Plasticity in Rehabilitation: Reflex Conditioning and Brain – Computer Interfaces"
2010	Andrew R. Blight, PhD, Hawthorn, NY – "Therapeutic Development in SCI–A View from Industry"
2011	Gerben DeJong, PhD, Washington, DC – "Value-based Health Care and Innovation in SCI Health Management"
2012	William A. Bauman, MD, New York, NY – "Secondary Medical Consequences of SCI"
2013	Kristjan T. Ragnarsson, MD, New York, NY – "The 40th Anniversary of ASIA: Beginnings, Accomplishments and Future Challenges"

given the investigators the forum to present their findings and educate each other and all ASIA's members.

The US Government did not spontaneously and without encouragement create funding for the Model Systems. In 1968, Howard A. Rusk, MD, Frank Krusen, MD, and Murray Freed, MD, had met with members of the US Congress and spoke persuasively about the needs of persons with SCI and the inadequacy of clinical SCI services outside the VA system. Consequently, Congress mandated that RSA address the issue and recommend the appropriate course of action, which turned out to be creation of a continuum of care from the onset of SCI through long-term follow-up. In 1970, this led to the implementation of the first federally designated SCI Model System in Phoenix, Arizona, led by John M. Young, MD, who played a large role in the following years in implementing the Model System concept and organizing data collection and analysis. Much credit for the Model Systems early success should also be given to J. Paul Thomas, the RSA project manager, who delivered the inaugural Sell Lecture in 1982.

In 1972, 10 additional Model Systems were established, first in Birmingham, Alabama; Charlottesville, Virginia; Chicago, Illinois; and New York City, followed later that year by Boston, Massachusetts; Denver, Colorado; Houston, Texas; Minneapolis, Minnesota; Santa Clara, California; and Seattle, Washington. What really secured the future of the SCI Model Systems, then and now, was an important event in 1973, when Congress enacted legislation in Section 304 (b) (1) of the Rehabilitation Act authorizing continued development of the SCI Model Systems. Since that time, 28 institutions have received funding for SCI Model Systems and the common denominator for all of them has been the investigators' involvement in ASIA. Currently, 14 Model Systems are funded by the National Institute on Disability and Rehabilitation Research (NIDRR).

In 1972, many of the leaders of the new SCI Model Systems met in June, August, and December to discuss the strengths and weaknesses of each system, as well as their common goals. At the meeting, the group decided to name itself the Melbourne Society (sic!), apparently because one influential member, Dr. David Cheshire, had recently immigrated from Australia to the United States.[1] By the end of the year 1972, it was clear that a more formal organization was needed and John Young, Paul Meyer, and Terry Carle were appointed to an ad hoc committee to select a name for the organization and develop its by-laws. At the first official membership meeting in Chicago in February 1973, the new organization was named American Spinal Injury Association (ASIA), which was approved by all 21 members present. The advantages of establishing such an organization were later described by Carter:

- Impact both public and professional education
- Develop guidelines for allied health personnel participating in SCI care
- Establish a common SCI center database
- Develop a common SCI nomenclature
- Critique the assets and deficits of SCI centers participating in ASIA

The three committees of ASIA were established: Constitution and Bylaws, Membership and Nominative, Program-Educational and Data Committees. Edward Carter was elected as Acting Chairman and Paul Meyer as Acting Secretary. At the next ASIA meeting, which was held in Denver in June of 1973, the ASIA bylaws were approved and ASIA's first board of directors and committee members were elected with Edward Carter serving as the first president (**Table 2**).

The second general ASIA meeting was held in Houston in February of 1974, followed in the same year by board meetings in Denver and Memphis, but at all of these meetings organizational matters were primarily discussed. The first Scientific ASIA Meeting was held in New York City in May of 1975. I am happy to report that I, as a SCI Research Fellow, was among the approximately 40 attendees. Various topics were discussed (**Table 3**), but as I recall the senior members of the group had difficulty agreeing with each other on anything relating to the optimal care of the various conditions that affect persons with SCI. Each passionately believed that his approach was the only correct way to manage the condition; but still after a day of heated arguments, all the attendees got together in the evening for drinks and dinner,

Table 2. First Board of Directors and Committee Chairs for ASIA

- R. Edward Carter, President
- Shannon Stauffer, Vice President
- Paul R. Meyer, Jr, Secretary
- Terry V. Carle, Treasurer
- John S. Young, Chair, Data and Nomenclature Committee
- David Cheshire, Chair, Bylaws Committee
- Theodore Cole, Board Member
- Robert R. Jackson, Chair, Program Education Committee
- Glenn G. Reynolds, Chairman, Membership Committee

Table 3. Topics discussed at the first scientific meeting of ASIA

- Cardiovascular reflexes
- Venous thrombosis
- Bacteriuria vs urinary tract infection
- A bed or frame for conservative acute SCI management
- Unique case presentations
- Moderated open topics forum

showing nothing but love and respect for each other.

Since 1975, ASIA has held Annual Scientific Meetings and each one has been of great educational and scientific value. Attendance at these meetings rose steadily to an average attendance of close to 400 during the last decade. During the same time, ASIA membership grew to between 400 and 500. It is remarkable that ASIA membership has truly been multidisciplinary in nature. Initially, ASIA was exclusively a physician organization, but its members came from a number of medical specialties, such as Physical Medicine and Rehabilitation (PM&R), Orthopedic Surgery, Urology, Neurosurgery, Internal Medicine, Pediatrics, and Anesthesiology. Recognizing the value and contributions of nonphysicians in SCI clinical care, research, and education, ASIA opened its membership to all health professionals in 1990. Twenty physicians have served as presidents of ASIA (**Table 4**), most of whom have come from the specialties of orthopedics and PM&R.

Table 4. Past Presidents of ASIA

R. Edward Carter, MD, Medicine Houston, TX (1973-1977)	**Douglas E. Garland, MD, Ortho** Long Beach, CA (1999-2001)
Paul R. Meyer, Jr., MD, MM, Ortho Chicago, IL (1977-1981)	**Daniel P. Lammertse, MD, PM&R** Englewood, CO (2001—2003)
Samuel L. Stover, MD, PM&R Birmingham, AL (1981-1983)	**Jack E. Zigler, MD, Ortho** Plano, TX (2003-2005)
David F. Apple, Jr., MD, Ortho Atlanta, GA (1983-1985)	**Marcalee Sipski Alexander, MD, PM&R** Birmingham, AL (2005-2007)
J. Darrell Shea, MD, Ortho Orlando, FL (1985-1987)	**Glenn Rechtine, MD, Ortho** Rochester, NY (2007-2008)
William H. Donovan, MD, PM&R Houston, TX (1987-1989)	**Amie B. Jackson, MD, PM&R** Birmingham, AL(2008-2009)
John F. Ditunno, Jr., MD, PM&R Philadelphia, PA (1989-1991)	**Alexander Vaccaro, MD, PhD, Ortho** Philadelphia, PA (2009-2010)
Robert L. Waters, MD, Ortho Downey, CA (1991-1993)	**Michael J. Kennelly, MD, Urology** Charlotte, NC (2010-2011)
Kristjan T. Ragnarsson, MD, PM&R New York, NY (1993-1995)	**Lawrence C. Vogel, MD, Peds** Chicago, IL (2011-2013)
James S. Keene, MD, Ortho Madison, WI (1995-1997)	
Kenneth C. Parsons, MD, PM&R Englewood, CO (1997-1999)	

Table 5. Most important accomplishments of ASIA (survey of ASIA's past presidents)

1.	Developing the "Standards for Neurological Classification of SCI"
2.	Establishing the G. Heiner Sell Fund for Research and Education
3.	Organizing a high-caliber annual scientific meeting at a modest price
4.	Conducting joint scientific meetings with other professional organizations (ISCoS, ASCIP)
5.	Creating eLearning center for web-based education
6.	Influencing increase in Federal funding for the SCI Model System Program
7.	Broadening ASIA membership to include nonphysicians
8.	Establishing the ASIA Lifetime Achievement Award
9.	Creating a strong committee structure to implement ASIA's strategic plan
10.	Initiating with PVA the development of SCI Clinical Practice Guidelines
11.	Providing ASIA members with an official journal, ie, *Topics in Spinal Cord Injury Rehabilitation*

ASIA's Most Significant Accomplishments

It would be difficult to describe in detail all the major accomplishments of ASIA over last 40 years, but after surveying ASIA's past presidents, a list of the top 11 was developed (**Table 5**), each of which deserves a brief description.

1. *Development of the "International Standards for Neurological Classification of Spinal Cord Injury"* stands among ASIA's greatest achievements. From ASIA's inception, its members agreed that accurate communication among clinicians as well as among researchers requires a standard and widely accepted classification system. Early attempts to classify SCI revealed great differences of opinion, especially with respect to an accurate description of the most consistent dermatomes and myotomes for each neurological level. After careful consideration, the ASIA Board of Directors agreed in 1982 to publish the first "Standards," but these were followed by several refinements and revisions,[3] the last such revision being in 2011. A major milestone was reached in 1992, when the International Medical Society of Paraplegia (IMSoP), the former name of the International Spinal Cord Society (ISCoS), endorsed the "Standards," which are now used all over the world by clinicians and researchers alike, having been translated into 15 different languages. In 1994, a 200-page teaching manual and four videotapes were developed as a teaching package to ensure accurate use of the "Standards."
2. *The G. Heiner Sell Fund for Research and Education* has permitted ASIA to invite many of the world's leading scientists and clinicians to present their cutting edge work in their search for cure of SCI or for better care. It is remarkable that the now sizeable Sell Fund Endowment was created entirely by ASIA members and by Dr. Sell's family and his friends. Prudent investments and additional contributions over the years have permitted the Fund to expand its original purpose and support in a modest way research projects and programs of educational value.
3. *ASIA's Annual Scientific Meetings* have been of high caliber from their beginning in 1975. At most of these meetings, scientific papers have been presented in different "sections," each focusing on a specific aspect of SCI care. In addition, there have been poster sessions with a broad scope, instructional courses, and the Sell Lecture. Between 1991 and 2010, abstracts of the scientific papers were published in the *Journal of Spinal Cord Medicine*, but since 2011 these have appeared in *Topics in Spinal Cord Injury Rehabilitation*.

4. *Conducting joint scientific meetings with other organizations.* Over the years, ASIA has collaborated with numerous organizations on various matters affecting the care of persons with SCI, including the PVA, various medical or specialty organizations, other SCI medicine societies, etc. In 1989, ASIA held its first joint meeting with another organization, which was the American Paraplegia Society (APS), in Las Vegas, Nevada. In 2009, another joint meeting was held with APS and its sister societies with the collaboration and support of the PVA. ASIA members have also worked closely with IMSoP/ISCoS to secure an international agreement on ASIA's "Standards for Neurological Classification of SCI." In addition, ASIA has held three combined scientific meetings with ISCoS, in Vancouver, British Columbia, Canada (2002), Boston, Massachusetts (2006), and in Washington, DC (2011), with the fourth joint meeting planned for 2015. Two of ASIA's past presidents have served as presidents of ISCoS: Edward Carter and William Donovan.
5. *Creating the eLearning Center.* During the last decade, computer-based learning has been growing in popularity. In 2006, ASIA's Board decided to develop a Web-based interactive curriculum relating to SCI, that is, the eLearning Center, in order to enable clinicians to perform accurate and consistent neurological examinations of persons with SCI. The first "module" in the series is referred to as "International Standards Training eLearning Program" (InStep), which teaches the use of the Standards for Neurological Classification with test cases, followed by questions and answers, permitting the user to learn at his or her own speed and revisit the curriculum as needed. Access is without charge, but a certificate is available for a nominal fee. The second module developed was WeeSTeP, addressing care of children with SCI, followed by ASTeP, which teaches the use of autonomic classification of persons with SCI. The fourth module is SpaSTeP, dealing with spasticity treatment. These modules have been funded in large part by grants from different organizations, such as Medtronic (InSTeP), Shriners Hospitals (WeeSTeP), Craig Neilson Foundation (ASTeP), and Allergan (SpaSTeP). However, the production of these modules depends on the work of ASIA members using their clinical and scientific backgrounds.
6. *Influencing Federal funding of SCI Model System program.* In 1994, NIDRR's budget called for reduction of funding for the SCI Model Systems program from $4M to $3M annually. This meant that the number of funded Model Systems would have to be reduced. In response to this development, ASIA organized a lobbying campaign with the help of its legislative attorney, Richard Verville, and with moral support of PVA. ASIA members in states across the country met with their representatives in the US Congress to solicit their support, hoping that some of them might take a lead in support of the program.Through the efforts of ASIA members in the State of Washington, US Senator Slade Gorton sponsored legislation with the firm support of US Senator Arlen Specter of Pennsylvania to dramatically raise, not reduce, the funding of the SCI Model System program to $7M annually. This level of funding has held steady ever since and has permitted an increase in the number of funded SCI Model Systems. In addition, ASIA members have at various times met with and expressed their views to numerous officials in the US government and Congressional staff members.
7. *Nonphysician members of ASIA.* The complete care of persons with SCI requires the expertise of different medical specialists as well as that of various allied health professionals. ASIA was a physician-only organization until 1990, although many nonphysicians presented scientific papers at the annual meetings, which made clear the importance and value of nonphysician colleagues involved in SCI care and research.

Table 6. Recipients of ASIA Lifetime Achievement Award

1987	John M. Young, MD	2002	Kristjan T. Ragnarsson, MD
1990	A. Estin Comarr, MD	2003	Jerome M. Cotler, MD
1991	R. Edward Carter, MD	2005	William H. Donovan, MD
1992	Albin T. Jousse, MD	2006	Hans L. Frankel, MD
1993	Samuel L. Stover, MD	2007	Robert L. Waters, MD
1994	J. Paul Thomas		Gale G. Whiteneck, PhD
1996	Alain Rossier, MD	2008	J. Darrell Shea, MD
1997	David F. Apple, Jr, MD	2009	Randal R. Betz, MD
1998	Paul R. Meyer, Jr, MD, MM	2011	Charles H. Tator, MD
1999	Theodore M. Cole, MD	2012	Daniel P. Lammertse, MD
2000	John F. Ditunno, Jr, MD	2013	Lesley M. Hudson, MA
2001	Henry B. Betts, MD		

As a result, ASIA broadened its membership to include all SCI health care professionals in 1990. This has strengthened the organization and helped it to better pursue its mission and meet its goals.

8. *ASIA Lifetime Achievement Awards.* Most organizations give awards to worthy individuals. In 1987, ASIA first awarded its Lifetime Achievement Award in recognition of outstanding contributions in the field of SCI Medicine to John M. Young, MD. Since that time, 20 other individuals have received this award (**Table 6**). Additionally, ASIA has established the Sam Schmidt-Sell Fund Award, which was first awarded in 2009 to support research in the field of SCI medicine. In 2007, the Apple Award, named in honor of David M. Apple, Jr, MD, Past President of ASIA, was created to recognize an outstanding scientific publication in the field of SCI medicine.
9. *Committee structure in support of strategic plans.* Every few years, the ASIA Board has reviewed the strategies to accomplish its mission and goals and accordingly developed a strategic plan for the following 3 to 5 years. The committee structure has changed somewhat over the years, but it has consistently been geared to implement the strategic plan. The current ASIA committees are listed in **Table 7**.
10. *Development of SCI Clinical Practice Guidelines.* By the early 1990s, Clinical Practice Guidelines (CPGs) for different medical conditions had been developed and published by many leading professional organizations. ASIA's leadership recognized the need for such guidelines for SCI, but the cost was clearly prohibitive given ASIA's limited financial capacity. Fortunately, in 1995 ASIA's leadership was able to negotiate with PVA that PVA would fund the development of CPGs for SCI-related conditions while ASIA would lead the way to organize a scientific approach to the task. Subsequently, a CPG steering committee was created ultimately with representatives

Table 7. ASIA committees (2013)

- Autonomic Standards
- Bylaws
- Directors Nominating
- Education
- FOSA/COMSS Advisory
- International Standards
- Journal
- Membership
- Pediatrics
- Program
- Prevention
- Rehabilitation Standards
- Research and Awards
- Spine

from 24 different organizations of health care professionals involved in care of persons with SCI. This group has been referred to as the "Consortium for Spinal Cord Medicine" and Kenneth Parsons, MD, then the Vice President of ASIA, served as its first chair. The Consortium guides and monitors the CPG process, identifies and prioritizes the CPG topics, selects members of the expert panels, and works with the PVA staff on dissemination of the CPGs. Since 1995, 11 different SCI-CPGs and five Consumer Guides have been published and many of them have been revised, republished, and translated into Spanish. These CPGs have greatly influenced and improved the management of SCI-related conditions.

11. *Providing ASIA members with an official journal.* It has long been the dream of ASIA members to have an official scientific journal for ASIA. Two of ASIA's sister organizations have their own official journals; since 1962, ISCoS has had *Spinal Cord*, which was initially named *Paraplegia*, and since 1978, APS has had the *Journal of Spinal Cord Medicine*, originally named the *Journal of the American Paraplegia Society*.[4] Although ASIA members have played prominent roles on the editorial boards of both of these journals and submitted numerous scientific publications, these have not been the official journals of ASIA. In recognition of ASIA's contributions, the ASIA logo appeared on the inside or front cover of the *Journal of Spinal Cord Medicine* between 1999 and 2011. In 2011, ASIA made a three-year contract with Thomas Land Publishers, which made *Topics in Spinal Cord Injury Rehabilitation* the official journal of ASIA. *TSCIR* was first published in 1995 with David Apple, Past President of ASIA, serving as its Editor and Lesley Hudson as Associate Editor. Dr. Apple described in his forewords for the first issues that this would be a topical publication,[5] "presenting a well rounded view of subject intrinsic to the practice of SCI medicine."[6] The journal has followed this vision while addressing a wide range of SCI topics ever since. In the fall of 2011, James Krause, PhD, an ASIA member, became the new editor of the journal.

Clinical Accomplishments in SCI Care, 1973-2013

As an organization, ASIA has accomplished much over its 40-year history. In my opinion, its main impact has been to improve SCI care in the United States and internationally. Where there was great disorder and disagreements on virtually every aspect of SCI care, ASIA and the Model Systems have brought a universally accepted management approach to the various conditions associated with SCI, often with measurable improvement in outcomes. ASIA meetings have served as a vehicle of education and facilitated the personal interactions of SCI experts. ASIA members have not kept their knowledge to themselves, but have reached out to other organizations and their members in order to share their knowledge and learn from colleagues who are not ASIA members.

In the remainder of this lecture I would like to discuss the most significant progress made in the acute care and medical rehabilitation of persons with SCI during the last 40 years; for all this time, I have been involved in the care of persons with SCI. This is a very large subject and my presentation should be considered a brief overview. I will attempt to compare the way we practiced during the 1970s to what we can offer our patients today. The wheels of science move slowly; one must step back in order to appreciate the progress we have made.

Search for cure of SCI

While members of ASIA have been striving to improve the clinical care of persons with SCI with considerable success, neuroscientists have been searching for the cure of SCI with little to offer clinicians. Numerous interesting discoveries at have been made in animal experiments, but unfortunately these have not been shown in numerous clinical trials to improve the neurological recovery in humans with SCI. A senior investigator recently went so far as to write a review article in 2012 entitled "Central Nervous System Regeneration Does Not Occur,"[7] concluding that research should focus on the intact central nervous system rather than the cord lesion itself. It is unfortunate that today there is no treatment that verifiably changes the neurological outcome after SCI. Regardless, basic neuroscience research must continue for the long-term goal of finding even a partial cure of SCI.

SCI information and education networks

When ASIA and the SCI Model Systems program were founded in the early 1970s, the APS had been dormant for many years and the only active professional organization for physicians caring for patients with SCI was IMSoP/ISCoS, which had relatively few American members. The PVA, a consumer organization founded and operated by US veterans, focused exclusively on the needs of veterans. No books or informational brochures on SCI existed to guide patients and families or persons with SCI. The first textbook on SCI for physicians was published in 1973 written by Sir Ludwig Guttmann, evidently by him alone. There were no formal training programs available in SCI medicine, and educational courses were few and mostly poorly attended. The physicians involved in SCI care seemed to disagree on most issues ranging from classification of SCI to patient care.

Fortunately, this all changed with the birth of ASIA and the SCI Model Systems and later by the revival of APS as well as with infusion of federal funding for SCI clinical research. Stimulated by these developments, the "International Standards" were developed and approved by worldwide consensus, major textbooks on SCI were written, Spinal Cord Medicine became ACGME-approved as a medical subspecialty that required 1 year of formal training, Clinical Practice Guidelines were developed addressing the main conditions associated with SCI, an abundance of educational materials for persons with SCI and their families was produced, three major professional journals in SCI are currently published with monthly, bimonthly, or quarterly issues, several major SCI professional conferences are held annually, and so forth. These developments have had a major beneficial impact on the care of persons with SCI as will be discussed in the remainder of this presentation. Some of these developments have been previously described elsewhere.[8]

Early care of the fractured spine and injured spinal cord

The role of surgery in the management of acute of SCI was frequently debated during the 1970s. Reduction, or restoration of the normal alignment of the fractured spine, was generally obtained in a closed fashion by applying traction along the axis of the spine, but rarely by an open surgical approach. Spinal fractures could also be reduced by carefully placing the spine into extension for kyphotic angulations or, conversely, in flexion for lordotic angulations. Cervical traction was achieved by means of a head halter or placement of Crutchfield tongs secured to the skull through burr holes, and then connecting these by a cable to weights of 7 to 10 pounds. Surgical reduction and internal fixation had been advocated by Holdsworth,[9] but was rarely done. Because the Halo orthosis, which allowed early mobilization out of bed, had not yet been introduced, "conservative treatment of cervical spine injury by bed rest for weeks or months is universally used."[10] The average period of bed rest to permit healing of spinal fractures was 10 to 12 weeks, usually spent on a Stryker frame, Circolectric bed, or some modifications of these. With such a conservative approach, stability of the spine, as assessed by flexion-extension films, was usually achieved in that time span, unless a complete dislocation without an associated fracture, causing rupture of all segmented ligaments, had occurred, in which case surgical fusion was indicated. Surgical intervention, as advocated by Holdsworth, was felt to be fraught with complications unless undertaken by experts[11] and thus was cautioned against. In the rare instances when surgery was indicated, it was done weeks after the injury. Laminectomy to decompress the injured spinal cord was controversial even then and was later shown to increase spinal instability, and thus it was largely abandoned. Anterior, rather than posterior, surgical approach to cervical fractures was generally favored for reduction, decompression, and stabilization. Implanted instruments to stabilize the spine were not yet available, so spinal fusion was obtained by grafting bone chips or bone plugs at the fracture site. The 10 to 12 weeks of bed rest, while waiting for the spinal fracture to heal, obviously delayed the start of rehabilitation and resulted in many complications associated with SCI and bed rest.

Much has changed with respect to early surgical management of spinal fractures associated with neurological loss. Instead of nonsurgical reduction of the fracture followed by 10 to 12 weeks of bed rest with spinal immobilization, it has become customary to perform early open surgical reduction, decompression of the neural elements, and spinal stabilization by anterior rather than by posterior approach. Such surgery may now be done emergently or within a few days of the injury rather than weeks later. A large number of differently designed implanted spinal instruments made of steel or other metals have been developed both for the cervical and thoraco-lumbar parts of the spine. An early example of such instruments was Harrington rods, which were first used for correction of scoliosis in the 1960s and became commonly used for spinal fractures during the mid to late 1970s. Implanted instruments maintain alignment and stabilize the spine while bony fusion occurs. Internal fixation of the fractured spine has allowed the patient to be mobilized out of bed and to begin rehabilitation therapies much earlier than before. In some cases, the surgical stabilization is judged to be so secure that minimal or no external orthotic support is required. Nonoperative treatment still has its proponents, especially for stable fractures of the thoracic spine, which inherently are more stable due to the supportive function of the rib cage. Judging the degree of instability of the fractured spine early has also become more reliable after Denis introduced and defined the concept of the three columns of the spine in 1984.[12] The early surgical interventions of the fractured spine have not been shown to alter the neurological outcomes, but they have significantly reduced length of stay (LOS) on the acute services from 24 days in the 1970s to 11 days during the last 7 years,[13] as well as the total LOS.

Rehabilitation and clinical care of persons with SCI

When comparing clinical care and outcomes 40 years ago to current practices and results, it is clear that much has been accomplished. Fundamentally, this is evident in better health enjoyed by most persons with SCI, greater life expectancy, as well as increased mobility, participation, and presumably quality of life. In this regard, members of ASIA and the SCI Model Systems have much to be proud of. Contributions made by clinical investigators within the VA hospital system and colleagues abroad also need to be recognized. During these 40 years, the national and international communities of SCI professionals in various medical specialties and allied health fields have become a cohesive and interactive group, sharing freely with each other knowledge and ideas that may help people with SCI.

Improved SCI care has resulted in fewer medical complications and decreased mortality, which are reflected in much shorter initial hospital LOS and fewer and shorter rehospitalizations. Data from the SCI Model Systems showed that average LOS in the 1970s was 114.8 days compared to 65 days for the time period from 2002 to 2009.[14-16]

Increased life expectancy of persons with SCI is clearly related to their better medical management and improved health. Prior to World War II, patients with SCI "usually died very soon from spinal shock or within a year from urinary, pulmonary, and other complications,"[17] but during and after World War II improved SCI care resulted in increased life expectancy. Since the 1970s, there has been a slow and modest increase in life expectancy of persons with SCI, most significant for ASIA A, C1-4 ventilatory dependent persons (**Table 8**).[16]

Table 8. Life expectancy after SCI (AIS A)

	1973-79	2000s
C1-4 ventilator dependent	4.4 years	20 years
C5 tetraplegia	33.5 years	36.9 years
T12 paraplegia	37.4 years	41 years

AIS = ASIA Impairment Scale.

Paralysis

Although paralysis still cannot be cured, compensatory methods to restore mobility have greatly improved since the 1970s. For most, manual and powered wheelchairs remain the standard equipment for locomotion, but these have vastly improved in design and construction. Manual wheelchairs today are much lighter in weight and easier to maneuver than earlier models and modern powered wheelchairs provide various options, which include fully reclining and stand-up mechanisms. Numerous designs of knee-ankle-foot orthoses (KAFOs) have been introduced, but none of these have made it possible for people with complete paraplegia or tetraplegia to ambulate independently for any significant distances. Regardless of the KAFO's design, the large energy consumption associated with such ambulation has limited the use of such orthoses. Several functional electrical stimulation (FES) systems designed for ambulation have been developed over the last 20 years, but none of these have enjoyed widespread use. A somewhat controversial development has been the use of body weight–supported treadmill training (BWSTT); it has been shown in some studies to restore limited ambulation skills for persons with neurologically incomplete SCI, [18] although other studies have not shown this intervention to be any better than conventional overground training.[19,20] Another study has shown that epidural electrical stimulation of the lumbosacral spinal cord in humans can unlock the ability of the spinal cord to control movements and thus permit standing and assisted stepping.[21]It is felt that the spinal cord has a considerable level of automaticity for locomotion and is responsive to task-specific sensory cues; with repetitive training, this ability may generate appropriate motor responses without any input from supra-spinal centers.[22]Another encouraging development has been the introduction of the variety of microprocessor-controlled battery-powered exoskeletal robotic devices, which are being clinically tested with the goal of enabling persons with SCI to ambulate with less energy expenditure than the traditional KAFO.[23]

Modern technology has enabled persons with SCI to increase their participation in community activities through their use of environmental control systems, computers, and voice-controlled devices. The experimental brain-computer interface may enable people with high-level tetraplegia to use the brain's electrical signals to power a robotic arm[24] and perhaps other electrically powered devices.

Sensory loss after spinal cord injury

Sensory loss after SCI cannot be restored by any known intervention, but many people with SCI become quite adept in using their sight, hearing, and attention skills to compensate in part for the loss of sensation.

Neurogenic bladder

Management of the neurogenic bladder has changed significantly since the early 1970s, even if its basic goals have not changed, that is, preventing urinary incontinence and complications. Until the early 1970s, an indwelling catheter was usually maintained for a long period of time, even permanently. This was especially true for women who could not be fitted with an external urinary receptacle. During the rehabilitation process, a "bladder training" program was started,[25] which consisted of tidal drainage, frequent clamping of the catheter, and trial of voiding. For those men able to spontaneously void, there were primitive external catheters, consisting of ordinary condoms that were attached to the penis with a commercial glue. The condom was then attached to a rubber tube that was connected to a urinary bag. Urecholine was commonly used to stimulate bladder contraction and thus to facilitate voiding, often creating excessive intravesical pressure and ureteral reflux. Transurethral external sphincterotomy, often combined with the resection of the bladder neck (TURES), was frequently done to reduce bladder outlet resistance and facilitate more complete bladder emptying at a low intravesical pressure via external condom drainage.[26] Urinary complications were common and were the most common cause of death after SCI.[27]

Currently, the intermittent catheterization is started as soon as possible along with judicious fluid intake. A variety of modern catheters are now available as well as sophisticated external catheter systems that are easy to apply and remove. Pharmacotherapy to suppress excessive bladder contractions and associated increase in bladder pressure now plays a major role, whereas urecholine is rarely used. For specific urinary problems, a variety of elective reconstructive surgical procedures may be done, such as urinary diversions, bladder augmentation, insertion of ureteral stents, and even placement of anterior sacral roots electrical stimulation systems. TURES is now rarely done. Botulin toxin injections to reduce spastic contractions of the external bladder sphincter have recently been gaining in popularity. As a result of modern urinary management, there has been a dramatic decrease in the mortality due to urological complications, which are now number 11 on the list among the most common causes of death after SCI.[28]

Neurogenic bowel

Neurogenic bowel management has not changed significantly over the years. It still aims to establish predictable, timely, and complete evacuation of stools without incontinence. Ineffective bowel management adversely affects the quality of the life and social acceptance of persons with SCI, in addition to causing physical and emotional discomfort. Fundamentally, sufficient fluid intake and balanced diet is important, but with use of digital stimulation of the rectum to initiate evacuation, a reliable bowel evacuation routine may be created without any medications. However, more often certain bowel medications are used, including stool softeners, bulk formers, peristaltic stimulants, laxatives, contact irritants, suppositories, and mini enemas. When establishment of a bowel routine fails and stool incontinence is significant, surgical interventions may occasionally be indicated, for example, colostomy or the recently introduced Malone antegrade continence enema procedure.[29]

Sexual function and fertility

For a long time, impaired male sexual function and fertility were perhaps the most stigmatizing and feared conditions associated with SCI. Decreased or absent genital sensation is common and usually associated with erectile, orgasmic, and ejaculatory impairment. In addition, the semen quality is poor, all of which combine to severely reduce male fertility. In 1973, Guttmann reviewed several studies on male sexual function and fertility and noted that 52% to 94% could achieve erections, 22% to 33% were capable of intercourse, 6% to 14% were able to reach orgasm, and less than 5% were able to reproduce.[30] Clearly, even when able to achieve erection, these were often unsustained and insufficient for intercourse. During the 1970s and 1980s, efforts to improve male sexual function included implantation of penile prostheses, injections of vasoactive agents into the corpus cavernosus, and application of vacuum erection devices,[31] but since the 1990s these interventions have been largely replaced by use of oral medications, such as sildenafil, which have restored erection and intercourse capabilities in 87.5% and 66%, respectively, of men with SCI.[32] However, these drugs do not improve orgasmic and ejaculatory function or increase fertility, which require different interventions. For that purpose, electrical or vibratory stimulation has been shown to help as many as 86% of men with SCI to achieve orgasm and ejaculate; with artificial insemination, pregnancy rate has rapidly increased and been reported as high as 74% in recent studies.[33] Sperm may also be retrieved by epididymal aspiration or by testicular biopsy followed by insemination or in vitro fertilization.

Sexual function and reproductive health in women has been studied far less than in men. During the 1970s, it was known among clinicians that women with SCI lacked genital sensation, but they regained their menstrual periods soon after injury and again became fertile. Only during the last two decades has the sexual function of women with SCI been scientifically assessed and studied.[34-36] These studies have shown that most women with SCI become sexually active following SCI, but their sexual activity is affected by both physical and emotional issues, such as impaired arousal, diminished vaginal lubrication, difficulty in achieving organism, low desire and self-esteem, etc. Since fertility is not affected in women with SCI, they should use birth control measures, if they do not desire to become pregnant. However, if they do become pregnant, the pregnancy and delivery should be considered of high-risk nature, especially among women with tetraplegia.[37,38]

Spasticity

The understanding and management of spasticity has improved significantly since the 1970s. Before and during the early 1970s, the phenomenon of spasticity was perplexing to most clinicians. However, it was known then to be related to upper motor neuron damage and to have a tendency to fluctuate in intensity depending on some poorly understood factors. It could not be measured and responded poorly to most medications. Diazepam was known to be effective, but it had side effects, which were often unacceptable. Dantrolene sodium arrived on the market during the 1970s and was shown to have significant anti-spasticity effect, but it was hepatotoxic in large doses, causing death in several patients with SCI, and thus physicians were discouraged from prescribing it. Destructive neurosurgical procedures were considered and sometimes done for the most severe spasticity, for example, cordectomy, rhizotomies, neurectomies, etc.

During the last 25 years, the understanding, assessment, and management of spasticity have greatly improved. The Ashworth Scale to measure the severity of spasticity was first developed during the 1960s,[39] but other scales felt by some to be more accurate have been described since.[40] Spasticity can now be much more effectively treated than before with pharmacological agents that have been introduced during the last 30 years. Oral baclofen has been used since the early 1980s with intrathecal administrations since the late 1980s. It has been shown to be remarkably effective, especially when administered intrathecally by a surgically implanted programmable pump, which has virtually eliminated the need for other surgical procedures for SCI-related spasticity. Oral tizanidiane, an alpha 2-adrenergic agonist, has also been found to be effective and sometimes better tolerated than other medications. Chemical neurolysis by alcohol and phenol injections has been largely replaced by selective injections of botulinum toxin.

Pain

Pain associated with SCI unfortunately remains common, difficult to treat, and adversely affects quality of life. During the 1970s, clinicians recognized several types of SCI pain, but they could not agree how it should be properly classified and how its severity should be measured; both deficiencies made it difficult to study SCI pain scientifically. Neuropathic SCI pain was known to be the most difficult type to treat as it responded poorly to nonsteroidal anti-inflammatory drugs (NSAIDs) and other medications frequently used at that time, such as diazepam, phenytoin, and propoxyphene, which often had side effects that were poorly tolerated. Narcotics were to be avoided, since it was widely believed that they were likely to lead to addiction, failed rehabilitation, and unsuccessful community integration.

Today, newer medications are available to treat neuropathic SCI pain, such as gabapentin, pregabalin, tramadol, and certain antidepressants. These generally have fewer side effects than the older medications, but it is not clear if they are more effective. Narcotics, which were to be avoided in the 1970s, can now be safely and carefully prescribed for persons with SCI pain, if they do not appear to be at risk for addiction. Research on SCI pain has been facilitated by the development of the International SCI Pain Basic Data Set,[41] the proposed International Classification of SCI Pain, and several scales to measure pain severity.[42]

Pressure ulcers

Pressure ulcers have been and continue to be a threat for persons with SCI, affecting their quality of life and community activities. In 1947, it was reported that pressure ulcers developed in 85% of persons with SCI.[43] Even during the early 1970s, pressure ulcers were so common after SCI that it was generally felt that they were impossible to prevent. Today, pressure ulcers can usually be prevented with frequent pressure relief, position change, skin inspection, and sometimes with the use of special mattresses and seating systems. Development of a severe pressure ulcer in a hospitalized person today is considered a liability. Clinically, it makes a large difference if a pressure ulcer is of grade I or II versus III or IV, as healing times and interventions will be profoundly different. The differences in the severity of pressure ulcers make it difficult to interpret data on their incidence and prevalence, as these data may not distinguish between the different grades. SCI Model Systems data show the incidence of all grades of pressure ulcers during initial stay to have been 56.9% in 1982,[44] 23.7% in 1998,[45] and 33.4% in 2006 (Model Systems last available data).[46] The most recent data show that less than 10% of all pressure ulcers are of grade III and IV.[46] My personal recollection is that during the 1970s, pressure ulcers of grade III and IV were common on all acute and rehabilitation services among patients with SCI, whereas today they are hardly ever seen. The few grade III and IV pressure ulcers seen today tend to occur in people with SCI who have been living in the community and receiving insufficient care for a variety of reasons. Special wound care programs and reconstructive surgical procedures for the most severe pressure ulcers apparently have been effective in facilitating healing and preventing reoccurrence.

Heterotopic ossification

Heterotopic ossification (HO) has long been associated with SCI, but today it does not seem to present the same clinical challenges as it did during the 1970s, which may be attributed to more effective interventions. The specific etiology of HO remains unknown, but several factors may play a contributing role. HO severity varies significantly, from being subclinical to causing severe ankylosis and functional limitations. The reported incidence/prevalence has varied significantly from 16% to 53%,[47-49] but in general it was higher during the 1970s than it is today. Furthermore, my personal observations are that severe ankylosing HO is by comparison rare today. The diagnosis and treatment of HO has improved considerably. Elevated alkaline phosphatase and positive bone scan are still most important markers for early diagnosis, but ultrasonography and magnetic resonance imaging are also helpful. The treatment of HO in the early 1970s consisted of therapeutic ultrasound, diathermy, and passive range of motion exercises,[47] which were applied gently in order to avoid tissue injury. Forceful manipulation and surgical excision were reserved for the worst cases, but poor surgical outcome and reoccurrence of HO were frequent.

The treatment of HO has changed dramatically. During the late 1970s, Stover[49] reported that oral edidronate sodium was effective both for prophylaxis and treatment of HO. Although this drug has not been used prophylactically, it remains the main intervention for HO, administered either orally or intravenously as soon as diagnosis of HO is made and at the same time aggressive range of motion exercises are performed. When surgical excision of HO is done today, edidronate is administered postoperatively in high does, first intravenously along with antibiotics and then orally for up to 6 months[50] with incremental passive range of motion exercises. With this regimen, reoccurrence of HO is now rare.

Table 9. Incidence of deep vein thrombosis (DVT) and pulmonary embolism (PE) after acute SCI

Decade	DVT	PE
1960s	65%-100%	20%
1970s	14%-100%	5%-15%
1980s	14%-61%	4%-5%
1990s	14%	4%
2000s	15%	3.6%

Deep venous thrombosis and pulmonary embolism

Deep vein thrombosis (DVT) and pulmonary embolism (PE) continue to occur during the first several weeks or months after SCI and with less frequency thereafter. The reported incidence of DVT and PE is related to the efficacy of prophylactic management, but also to the severity of the neurological deficit and sensitivity of the diagnostic evaluation. During the 1960s, before DVT prophylaxis became routine, it appears from descriptions that the incidence of DVT was 65% to 100%, depending on the sensitivity of the diagnostic test and approximately 20% for PE (**Table 9**). During the 1970s, when DVT prophylaxis with subcutaneous heparin was becoming standard practice, the incidence started to drop. In 1976, Todd et al reported the incidence of DVT to be 14% when judged by clinical examination and 100% when assessed by using 125I-fibrinogen leg scan.[51] Since the 1980s, the incidence of DVT has been stable at approximately 15%, with PE occurring in approximately 4% of patients. The most commonly used diagnostic tool for DVT today is ultrasonography. It is probable that without prophylaxis with anticoagulants the incidence of DVT and PE would be much higher or similar to what it was in the 1960s. Leg compression hoses and inferior vena cava filters, which did not exist in the 1970s, are commonly employed today, but it is not entirely clear how these prophylactic interventions have affected the incidence of DVT and PE.

Respiratory insufficiency and pulmonary complications

Since the 1970s, the life expectancy of ventilatory dependent persons with tetraplegia has increased more than for any other group of persons with SCI. During the 1970s, people with SCI who required mechanical ventilation were hardly ever seen at rehabilitation centers, since most died at the scene of the accident or shortly thereafter. If they survived one year, their life expectancy was reported to be 4.4 years compared to 20 years today.[16] The role of ASIA members and the Model Systems in this favorable development has been substantial and related to improved care strategies that were developed in a series of three Model System workshops during the 1980s on the management of high quadriplegia.[52] An interesting observation, which was made in the 1990s, was that ventilator-dependent persons with tetraplegia require significantly higher tidal volumes than those without SCI.[53-55] Another major development in respiratory care has been the use of programmed electro-stimulation of the phrenic nerve or motor points in the diaphragm to enable select persons with tetraplegia and respiratory insufficiency to become ventilator free.[56,57]

Although the life expectancy of ventilator-dependent persons with SCI has increased, pulmonary complications continue to be the top cause of morbidity and mortality for persons with tetraplegia, who all have a degree of respiratory insufficiency, and these are currently the leading cause of mortality after SCI.[28]

Metabolic and endocrine conditions

During the 1970s, it was well known that persons with SCI develop osteoporosis[58] in the paralyzed limbs, and this condition often leads to fractures with minimal trauma.[59] It was also known that children with acute SCI frequently developed hypercalcemia and that men had reduced serum testosterone levels. Autonomic dysreflexia (AD) was a well-recognized condition, and investigators had measured AD-associated increased catecholamine levels. It was not known at the time that there are alterations in carbohydrate and lipid metabolism, that is, increased insulin resistance and decreased high-density lipoprotein (HDL) cholesterol,[60] which increase the risk for a person with SCI to develop diabetes mellitus and coronary artery disease. It is often felt that the altered carbohydrate and lipid metabolism may be related to the profound sedentary lifestyle of persons with SCI. This opinion emphasizes their need for regular physical exercise as well as their need for proper diet, weight control, smoking cessation, and lipid-reducing drugs. Unfortunately, few rehabilitation programs address these needs in a systematic matter.

Autonomic dysfunction

It was recognized during the 1970s that persons with tetraplegia and those with high-level paraplegia had altered autonomic functions,[58] which were clinically evident as bradycardia, orthostatic hypotension, isothermia, and, most significantly, life-threatening autonomic dysreflexia (AD). Although SCI clinicians recognized the symptoms of AD and would promptly initiate correct intervention, this condition and its treatment were generally unknown to other physicians. Thanks to the education of emergency medical personnel, patients with SCI, and their families, more people are now familiar with the symptoms of AD and its treatment. The treatment of AD is similar now to what it was in the 1970s, that is, prompt evacuation of a full bladder and rectum, identification and elimination of other noxious stimuli, sitting up the patient with AD to lower blood pressure, etc. Today there are available more effective fast-acting anti-hypertension drugs, such as nifedipine and nitroglycerin, which patients prone to AD should keep within reach. Formerly, AD was a frequently recognized or suspected cause of sudden death in persons with high-level SCI, but it now is a rare cause of mortality, which may be attributed primarily to greater awareness of this condition and its management.

Conclusion and Challenges

When ASIA was founded 40 years ago, American physicians caring for persons with SCI did not belong to any active organizations that focused specifically on the comprehensive needs of their patients with SCI, and therefore they had few opportunities to meet to share their knowledge and experiences. As a result, clinical care of persons with SCI varied considerable across the country, and it is probable that treatment outcomes may have differed as well. After the foundation of ASIA and the establishment of the SCI Model Systems, physicians from several medical and surgical specialties met regularly at well-organized meetings to develop the best clinical approaches to SCI care from its onset through the life of the individual. Between these meetings, members of ASIA leadership would collaborate to develop materials that would facilitate communication, education, and research, such as the "International Standards for Neurological Classifications of SCI," the eLearning Center, the SCI CPGs, textbooks, book chapters, official journal, etc. As a result, the practice of SCI medicine has developed into a field that has solid scientific foundations. Collaboration and joint meetings with other organizations, such as APS, ISCoS, PVA, EPVA, and various specialty societies, have helped to spread the knowledge gained and thus contribute to better care worldwide.

As the medical care of persons with SCI became well established, it became evident that their psychosocial and vocational needs were often inadequately met. Soon after ASIA was founded, allied health professionals, both clinicians and researchers, made presentations relating to their field of expertise at the annual scientific meetings of ASIA. It was therefore timely and natural to offer full ASIA membership to them in 1990, a development which has enriched the organization and broadened its approach to meeting the needs of persons with SCI.

It has long been the dream of ASIA members to see decades of basic research bear fruit in the search of reversing the neurological loss that follows SCI. Showing keen interest and support for such research, approximately half of the Sell Lectures have been delivered by basic scientists. However, despite their promising results in animal experiments, clinicians regretfully are still not able to offer patients with SCI any treatment that will improve their neurological condition.

In the absence of cure for SCI, clinicians have improved the management of SCI through clinical research and by learning and applying innovations made in other medical and surgical fields as well as in bioengineering. As a result of improved care, life expectancy has increased and mortality has decreased as suggested by shorter initial hospital LOS and fewer rehospitalizations. Technological advances have increased mobility, communication, and the reintegration of persons with SCI into society. Renal failure is now a rare cause of death after SCI, and there are effective interventions for spasticity, male sexual dysfunction and infertility, and HO. Furthermore, severe pressure ulcers have become much less common than before, indeed they are quite rare.

Despite such remarkable progress in clinical care over the last 40 years, ASIA and its members face numerous challenges. Research aimed to reverse the neurological loss after SCI must continue, but should be viewed as a long-term goal. Research using rapidly developing technology and a growing understanding of the healthy nervous system should be supported to enable persons with SCI to control powered devices and stimulate the nervous system for functional purposes. Most people with neurologically complete SCI still cannot walk or even ambulate with assistive devices. Those with tetraplegia at C6 or at a higher level still need assistance with self-care and, if ventilator-dependent, most individuals remain so. Bowel and bladder dysfunction and pain refractive to interventions affect the quality of life for too many. Only one-third of persons with SCI return to any kind of work, and living in the community is a continuous challenge for most. ASIA and its members must continue to argue for meaningful funding for both clinical and basic science research as well as for health insurance and disability policies that meet the comprehensive needs of persons with disability. ASIA members must be vigilant in adapting promising developments in other fields for the benefits of their patients. The elective leadership of ASIA, now and in their future, must constantly strive to meet the needs of its members and, through them, the needs of their patients.

REFERENCES

1. Carter RE. How "ASIA" evolved. *Model Systems SCI Digest*. Fall 1979:3-8.
2. Tate DG. Contributions from the Model Systems programs to spinal cord injury research. *J Spinal Cord Med*. 2002;25:316-330.
3. Waring WP, Biering-Sorensen F, Burns S, Donovan W, et al. 2009 Review and revisions of the International Standards for the Neurological Classification of Spinal Cord Injury. *J Spinal Cord Med*. 2010;33(4):346-352.
4. Murphy C. Historical perspective. JSCM: This journal's journey. *J Spinal Cord Med.* 2010;33(1):2-5.
5. Apple DF. From the editor. *Top Spinal Cord Inj Rehabil.* 1995;1(1):v-vi.
6. Hudson LM. Foreword. *Top Spinal Cord Injury Rehabil.* 1995;1(2):vii-viii.
7. Illis LS. Central nervous system regeneration does not occur. *Spinal Cord.* 2012;50:259-263.
8. Ragnarsson KT. Medical rehabilitation of people with spinal cord injury during 40 years of academic physiatric practice. *Am J Phys Med Rehabil.* 2012;91:231-242.
9. Holdsworth F. Fractures, dislocations, and fracture-dislocations of the spine. *J Bone Joint Surg.* 1970;52(8):1534-1551.
10. Braakman R, Penning L. *Handbook of Clinical Neurology. Vol. 26, Injuries of the Cervical Spine.* PJ Vinken and GW Bruyn, eds. Amsterdam/Oxford: North Holland Publishing Co; 1976:293
11. Bedbrook G. *The Care and Management of Spinal Cord Injuries.* New York, Heidelberg/Berlin: Springer-Verlag; 1981:43.
12. Denis F. Spinal instability as defined by the three column spine concept in acute spinal trauma. *Clin Orthop.* 1984;189:65-76.
13. Spinal Cord Injury Facts and Figures at a Glance. www.NSCISC.UAB.edu
14. Stover SL, Hall KM, DeLisa JA, et al. Systems benefits. In: Stover SL, Delisa JA, Whiteneck GG, eds. *Spinal Cord Injury: Clinical Outcomes from the Model Systems*. Gaithersburg, MD: Aspen Publishers; 1995:317-326.
15. DeVivo MJ. Sir Ludwig Guttmann Lecture: Trends in spinal cord injury: Rehabilitation outcomes from model systems in the United States: 1973-2006. *Spinal Cord.* 2007; 45:713-721.
16. DeVivo MJ. *The 2010 Annual Statistical Report for the Spinal Injury Model Systems*. Birmingham, AL: National Spinal Cord Injury Statistical Center.
17. Kessler HH. *The Principles and Practices of Rehabilitation*. Philadelphia, PA: Lea and Febiger; 1950:307.
18. Wernig A, Nanassy A, Muller S. Laufband (treadmill) therapy in incomplete paraplegia and tetraplegia. *J Neurotrauma.* 1999;16:719-726.
19. Wessels M, Lucas C, Eriks I, deGroot S. Body weight supported gait training for restoration walking in people with an incomplete spinal cord injury: A systematic review. *J Rehabil Med.* 2010;42:513-519.
20. Dopkin BH. Pilot studies of robotics suggest efficacy, but randomized clinical trials reveal little: Why? *Top Spinal Cord Inj Rehabil.* 2011;17(1):1-6.
21. Harkema SJ, Gerasimenko Y, Hodes J, Burdick J, et al. Effect of epidural stimulation of the lumbosacral spinal cord on voluntary movement, standing, and assisted stepping after motor complete paraplegia: a case study. May 20, 2011. www.thelancet.com
22. Roy RR, Harkema SJ, Edgerton VR. Basic concepts of activity-based interventions for improved recovery of motor functions after spinal cord injury. *Arch Phys Med Rehabil.* 2012;93:1487-1497.
23. Zeilig G, Weingarden H, Zwecker M, et al. Safety and tolerance of the Rewalk™ exoskeleton by people with complete spinal cord injury: A pilot study. *J Spinal Cord Med.* 2012;35(2):96-101.
24. Collinger JL, Wodlinger B, Downey JE, Wang W, et al. High performance neuroprosthetic control by an individual with tetraplegia. Published online December 17, 2012. www.the lancet.com
25. Comarr AE. The practical urological management of the patient of SCI. *Br J Urol.* 1959; 31:1-46.
26. Lee IY, Ragnarsson KT, Sell GH, Morales P, Whelan J. Transurethral bladder neck surgery in spinal cord injured patients. *Arch Phys Med Rehabil.* 1978;59:80-83.
27. Stauffer ES. Long term management of traumatic quadriplegia. In: Pierce PS, Nickel VH, eds. *The Total Care of Spinal Cord Injuries.* Boston, MA: Little Brown; 1977:81-102.
28. DeViVo MJ, Chen Y. Epidemiology of traumatic spinal cord injury. In: Kirshblum S, Campagnolo DI, eds. *Spinal Cord Medicine*. 2nd ed. Philadelphia: Wolters

Kluwer/Lippincott Williams and Wilkins; 2011:72-84.
29. Herndon CD, Rink RC, Cain MP, et al. In situ Malone antegrade continence enema in 127 patients: A 6 year experience. *J Urol.* 2004;172:1689-1691.
30. Guttmann L. *Spinal Cord Injuries: Comprehensive Management and Research*. 2nd ed. Oxford: Blackwell Scientific Publications; 1976:478.
31. Sipski ML, Richards JS. Spinal cord injury rehabilitation: State of the science, *Am J Phys Med Rehabil.* 2006;85:310-342.
32. Ergin S, Gunduz B, Ugurlu H, et al. A placebo-controlled, multicenter, randomized, double-blind, flexible-dose, two-way crossover study to evaluate the efficacy and safety of sildenafil in men with traumatic spinal cord injury and erectile dysfunction. *J Spinal Cord Med.* 2008;31:522-531.
33. DeForge D, Blackmer J, Garate C, et al. Fertility following spinal cord injury: A systematic review. *Spinal Cord.* 2005;43:693-703.
34. Charlifue SW, Gerhart KA, Menter RR, et al. Sexual issues of women with spinal cord injuries. *Paraplegia.* 1992;30:192-199.
35. Alexander MS, Bodner D, Brackett NL, et al. Development of international standards to document sexual and reproductive functions after spinal cord injury: Preliminary report. *J Rehabil Res Dev.* 2007;44:83-90.
36. Bughi S, Shaw SJ, Mahmood G, et al. Amenorrhea, pregnancy, and pregnancy outcomes in women following spinal cord injury: A retrospective cross-sectional study. *Endocrine Pract.* 2008;14:437-441.
37. ACOG Committee Opinion. Obstetric management of patients with spinal cord injury. *Int J Gynecol Obstet.* 2002;79:189-191.
38. Pereira L. Obstetric management of the patient with spinal cord injury. *Obstet Gynecol Surv.* 2003;58(10):678-686.
39. Ashworth B. Preliminary trial of carisoprodol in multiple sclerosis. *Practitioner.* 1964;192:540-542.
40. Hsieh JTC, Wolfe DL, Miller WC, et al. Spasticity outcome measures and spinal cord injury: Psychometric properties and clinical utility. *Spinal Cord.* 2008;46:86-95.
41. Widerstrom-Noga E, Biering-Sorensen F, Bryce T, et al. The International Spinal Cord Injury Pain Basic Data Set. *Spinal Cord.* 2008;46:818-823.
42. Dijkers M. Comparing quantification of pain severity by verbal rating and numeric rating scales. *J Spinal Cord Med.* 2010;33:232-242.
43. Kuhn WG Jr. Care and rehabilitation of patients with injuries of the spinal cord and cauda equina. *J Neurosurg.* 1947;4:40-68.
44. Young JS, Burns PE. Pressure sores in the spinal cord injured. In: Young JS, Burns PE, Bowen AN, McCutchen R, eds. *Spinal Cord Injury Statistics: Experience of the Regional Spinal Cord Injury Systems.* Phoenix, AZ: Good Samaritan Medical Center; 1982:95-105.
45. Chen D, Apple DF Jr, Hudson LM, et al. Medical complications during acute rehabilitation following spinal cord injury – current experience of the Model Systems, *Arch Phys Med Rehabil.* 1999;80:1397-1401.
46. National Spinal Cord Injury Statistical Center. *The 2006 Annual Statistical Report for the Model Spinal Cord Injury Care Systems.* Birmingham, AL: Author; 2006.
47. Venier LH, Ditunno JF Jr. Heterotopic ossification in the paraplegic patient. *Arch Phys Med Rehabil.* 1971;52:475-479.
48. Bolger JT. Heterotopic bone formation and alkaline phosphatase. *Arch Phys Med Rehabil.* 1975;56:36-39.
49. Stover SL, Hataway CJ, Zieger AG. Heterotopic ossification in spinal cord-injured patients. *Arch Phys Med Rehabil.* 1975;56:199-204.
50. Garland DE, Orwin JF. Resection of heterotopic ossification in patients with spinal cord injuries. *Clin Orthop Rel Res.* 1989;242:169-176.
51. Todd JW, Frisbie JH, Rossier AB, et al. Deep venous thrombosis in acute spinal cord injury: A comparison of 125i fibrinogen leg scanning, impedance plethysmography and venography. *Paraplegia.* 1976;14:50-57.
52. Whiteneck G, Adler C, Carter RE, et al. *The Management of High Quadriplegia*. New York: Demos Publications; 1989.
53. Peterson P, Brooks CA, Mellick D, Whiteneck GG. Protocol for ventilator management in high tetraplegia. *Top Spinal Cord Inj Rehabil.* 1997;2(3):101-106.
54. Berlly M, Shem K. Respiratory management during the first five days after spinal cord injury. *J Spinal Cord Med.* 2007;30(4):309-318.
55. Peterson WP, Barbalata L, Brooks CA, et al. The effect of tidal volumes on the time to wean persons with high tetraplegia from ventilators. *Spinal Cord.* 1999;37:284-288.
56. Glenn WW, Holcomb WG, McLaughlin AJ, et al. Total ventilatory support in a quadriplegic patient with radiofrequency electrophrenic respiration. *N Engl J Med.* 1972;286:513-516.
57. DiMarco AF, Onders RP, Ignagni A, et al. Inspiratory muscle pacing in spinal cord injury: Case report and clinical commentary. *J Spinal Cord Med.* 2006;29:95-108.
58. Naftchi NE. Metabolic dysfunctions following spinal cord injury. *Model Systems' SCI Digest.* 1980;2(4):17-28.
59. Ragnarsson KT, Sell GH. Lower extremity fractures after spinal cord injury: A retrospective study. *Arch Phys Med Rehabil.* 1981;62:306-310.
60. Bauman WA, Corsten MA, Radulovic M, et al. Thirty-first G. Heiner Sell Lectureship: Secondary medical consequence of spinal cord injury. *Top Spinal Cord Inj Rehabil.* 2012;18(4):354-378.